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TITLE: The Effects of Supportive and Nonsupportive Behaviors on
the Quality of Life of Prostate Cancer Patients and Their
Spouses

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FOREWORD

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INTRODUCTION

Research on prostate cancer has not, as yet, identified how patients' and their spouses' supportive (e.g., giving advice/emotional support) and nonsupportive behavior (e.g., criticizing/avoiding partner) affect and are affected by their: 1) feelings of disease uncertainty, 2) psychological well-being, 3) perceptions of control, and 4) quality of life (QOL). This two year prospective observational survey study explores these issues among approximately 150 early stage prostate cancer patients and their spouses. Specifically, early stage prostate cancer patients and their spouses are asked to complete a questionnaire packet before surgery (radical prostatectomy), and at one, six and 12 months post-surgery. The questionnaire packet assesses perceptions of disease uncertainty, supportive and unsupportive behaviors, perceptions of control, marital satisfaction, and quality of life. The specific predictions to be tested in the study are:

H1: Greater levels of illness uncertainty among prostate cancer patients and their spouses will predict significantly lower levels of perceived control.

H2: Patient and spouses with low levels of uncertainty and/or high perceived control will need primarily informational and social and instrumental support; individuals with high levels of illness uncertainty and/or low perceived control will need emotional, network and esteem support.

H3: Greater illness uncertainty and perceived inadequacies in social support, especially in areas most needed, will correlate positively with frequency and types of non-supportive behaviors.

H4: Social support and non-supportive behaviors will mediate the relationship between illness uncertainty and QOL, and between illness uncertainty and psychological well being.

H5: Higher levels of uncertainty and lower perceived control will predict poorer QOL, especially shortly after surgery.

H6: Spouses will experience poorer QOL than patients.

BODY

During the first year of the grant, we have achieved successfully many of our preliminary objectives as provided in our statement of work. These are listed below:

Task 1: Plan and develop a tracking system with the Duke Department of Urology to recruit study participants (months 1-2)

Progress: We have initiated and implemented a very successful recruitment procedure which has resulted in reaching close to 90% of all early stage prostate cancer patients (A & B) who visit the urology clinic.

Task 2: Develop and test study questionnaire with 10 prostate cancer patients and their spouses (months 1-2).

Progress: We have not only pilot tested this questionnaire, but have also designed the one, six, and twelve-month questionnaires. These questionnaires are exhibited in Appendices B – E. (The baseline questionnaire is presented in Appendices B. We have provided a copy of both the patient version and the spouse version of the baseline questionnaire. However, for the one, six, and twelve-month post surgery questionnaires, Appendices C – D, we have included only the patient version. The variance in the two questionnaires, spouse and patient, is minimal and thus remains consistent throughout the various time points.)

Task 3: Mail-out study questionnaires to 150 prostate cancer patients and their spouses along with reminder notices and phone calls (months 3-27).

Progress: We are in our final month of collecting baseline data, and in early October we will begin sending out our 12-month post-surgery follow-up questionnaire. As of September 15, 1999, we have tracked 256 patients through Dukes Urology Clinic. Of these 256 patients: 137 are enrolled, 38 are actively being recruited, 14 never sent back their questionnaire after all reasonable efforts were made, 16 refused to participate, and 51 were ineligible (28 chose treatment other than surgery, 9 diagnoses of another cancer within less than 5 yrs, 4 due to extenuating circumstances (i.e. surgical complications), 3 were mentally incompetent, 2 had recurrent prostate cancer, 2 had been diagnosed more than one yr. ago, 2 were prisoners and 1 patient was too advanced after clinical exam).

We have chosen to enroll patients that do not have a spouse or partner. These 13 patients were sent questionnaires without questions that assessed relationship constructs (e.g. social support, marital satisfaction).

On a few occasions we were unable to recruit patients before they had their surgery. However, due to their interest in participating these 5 patients were enrolled at the one-month post-surgery follow-up.

Along with the 137 patients that are currently enrolled in the study, 119 of their partners (spouses or significant others) have completed questionnaires and are enrolled in the study.

Table 1 summarizes the current recruitment data:

Table 1: Recruitment Summary as of September 15, 1999

Questionnaire Time point	Total Sent	Total Received	Patients with a Partner (2)	Patients with out a Partner (3)	Partners (4)	Matched Pairs (Dyads) (5)
Baseline	289	246	119	13	114	112
One month Follow-up (1)	194	180	82	5	82	81
Six Month Follow-up	86	74	35	5	34	34
Twelve Month Follow-up	0	0	0	0	0	0

- (1) Some patients who completed baseline questionnaires were lost at follow-up for various reasons. 26 patients were lost because their post surgical pathology report indicated advanced disease, 3 changed their treatment choice, and 1 was lost due to refusal. Thus, 98 patients remained eligible for the one-month follow-up as compared with 128 patients that were enrolled at Baseline and have had their surgery. 9 patients have not yet had their surgery.
- (2) This column represents the number of patients that completed the questionnaires who **have** a partner (spouse or significant other).
- (3) This column represents the number of patients that completed the questionnaires who **do not have** a partner (spouse or significant other).
- (4) This column represents the number of partners (spouses or significant others) that completed the questionnaires.
- (5) This column represents the number or couples (patients and their spouses or significant others) that completed the questionnaires.

Task 4: Conduct analyses on baseline data.

Progress: Baseline data analyses will begin during the first week in October. However, we have had an abstract based on preliminary analyses of 72 patients and their spouses, accepted to the Pan American Congress of Psychosocial and Behavioral Oncology Conference to be held October 20th – 23rd in New York City. This abstract is included in Appendix A.

Tasks 5-8: Conduct analyses on the one, six and twelve month post-surgical data and write-up overall project paper(s).

Progress: These activities will begin to take place starting in February of the year 2000.

KEY RESEARCH ACCOMPLISHMENTS

- We have initiated and implemented a very successful recruitment procedure which has resulted in reaching close to 90% of all early stage prostate cancer patients (A & B) who visit the Duke Medical Center's urology clinic.
- Developed and distributed to patients and their spouses the baseline, and one, six, and 12 month post-surgery questionnaires.
- Have achieved a very satisfactory return rate from patients; 85% at baseline, 86% at the one-month post surgery time point and 87% at the six-month post-surgery time point. The high return rate was similar among the spouses; 85% at baseline, 88% at the one-month post surgery time point and 85% at the six-month post-surgery time point.
- Will be presenting an abstract of baseline results to the Pan American Congress of Psychosocial and Behavioral Oncology Conference to be held October 20th – 23rd in New York City.

REPORTABLE OUTCOMES

Abstract entitled: "Correlates of Quality of Life Among Prostate Cancer Patients and Their Spouses" to be presented at the Pan American Congress of Psychosocial and Behavioral Oncology Conference to be held October 20th – 23rd in New York City

CONCLUSIONS

An in-depth analysis of our baseline data will commence shortly. However, based on very preliminary baseline data (pre-surgery) we are finding that:

- Women report poorer quality of life than the patient, especially in areas that involve emotional outcomes (e.g., mental health).
- The reported quality of life of the patient is correlated significantly with their perceptions of marital satisfaction, disease uncertainty, perceived spousal support and perceived spousal critical and avoidant behaviors. These outcomes are not consistently related to spouses' quality of life. Therefore, it may be the patient's perceptions of relational issues that may affect more powerfully his quality of life than that of the spouse.

REFERENCES

Not applicable at this time.

Appendix A

Abstract

"Correlates of Quality of Life Among Prostate Cancer Patients and Their Spouses"

Isaac M. Lipkus*, Elizabeth Clipp, Richard Potthoff , and

Cary Robertson

Duke University Medical Center, Durham, North Carolina, United States

There has been little research exploring how prostate cancer patients and their spouses' feelings of disease uncertainty, perceived social support, negative social interactions (i.e., critical and avoidant behaviors), and marital satisfaction affect their own and their partners' quality of life. We explored these influences among 72 early stage prostate cancer patients and their spouses shortly before having surgery (radical prostatectomy).

Patients' emotional and social well-being, as assessed by the SF-36, were most consistently related to perceptions of their disease uncertainty, spousal support, degree to which they viewed their spouses as critical and avoidant, and to marital satisfaction. Spouses' quality of life was related less consistently to their own perceptions of these outcomes. Patients with wives that expressed greater marital satisfaction reported enhanced emotional well-being. However, spouses' quality of life was unrelated to patients' perceptions of their own disease uncertainty, perceived spousal support, spouses' negative and avoidant behaviors and marital satisfaction. Patients reported better emotional well-being, more energy/less fatigue, and less bodily pain than reported by their spouses. These data suggest that in contrast to their spouses, quality of life among men with early stage prostate cancer, prior to surgery, is related strongly to their feelings of disease uncertainty, to the nature of support they feel from their spouses, and to the quality of their spousal relationships. Future studies aimed at assessing quality of life in men with prostate cancer should take accounts from both members of the spousal relationship, focusing especially on the nature of support experienced by men between diagnosis of prostate cancer and surgical intervention.

Appendix B

Baseline Questionnaires

Patient with a Spouse Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage paid envelope before your treatment for prostate cancer begins.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your wife, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at 919-956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / _____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. ☐ Living with spouse or partner
2. ☐ In a significant relationship, but not living together
3. ☐ Not in a significant relationship

A9. What is your current marital status?

1. ☐ Never married
2. ☐ Married
3. ☐ Separated
4. ☐ Divorced
5. ☐ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. ☐ Your husband/wife
2. ☐ Your mother
3. ☐ Your father
4. ☐ Your children 18 or under → How many? _____
5. ☐ Your children over 18 → How many? _____
6. ☐ Sister(s) → How many? _____
7. ☐ Brother(s) → How many? _____
8. ☐ Grandchildren → How many? _____
9. ☐ Grandparent(s) → How many? _____
10. ☐ Other relatives → How many? _____
11. ☐ Other non-relatives → How many? _____
12. ☐ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. ☐ 0 - \$4,000
2. ☐ \$4,001 - \$9,000
3. ☐ \$9,001 - \$18,000
4. ☐ \$18,001 - \$30,000
5. ☐ \$30,001 - \$40,000
6. ☐ \$40,001 - \$50,000
7. ☐ \$50,001 - \$60,000
8. ☐ Above \$60,000

A13. Altogether, how many people live on this income?

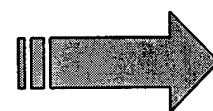
_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.		
Example: Asthma		No	Yes	Not At All	A Little	A Great Deal
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



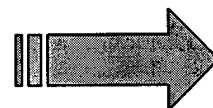
The following statements are about your thoughts and feelings since your diagnosis of prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each Treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my pain will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have pain, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE					
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C15	There are so many different types of staff, it is unclear who's responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C18	It is vague to me how I will manage my care after I leave the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	

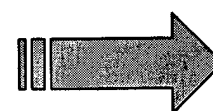
THOUGHTS AND FEELINGS		CIRCLE RESPONSE					
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C26	Because of the treatment, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C27	I'm certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C30	My physical distress is predictable; I know when it is going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C31	I can depend on the nurses to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	

Please continue to the next page of the questionnaire.



The following statements are about your sense of control over your life since your diagnosis of prostate cancer. Please circle the response that best describes how you think and feel since your diagnosis.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: Most of my problems are due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	There is no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	The really good things that happen to me are mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	I am responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	I can do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	Most of my problems are due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	I have little control over the bad things that happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	My misfortunes are a result of the mistakes I have made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	I am responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree



The next questions ask about marital attitudes and behaviors. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: Our marriage is strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	We have a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	My relationship with my partner is very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	Our marriage is strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	My relationship with my partner makes me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	I really feel like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6. On the scale below, indicate the point which best describes the degree of happiness, everything considered, in your marriage. Please circle the number that best represents your response.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10			
Very unhappy		Happy	Perfectly happy



In the space below, please answer the following questions.

F1. Since your diagnosis of prostate cancer, what has your wife said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way?

F2. Since your diagnosis of prostate cancer, what have you wished that your wife had done or said to help you cope with cancer that she did not do?

The statements below are possible reactions that you may have had towards your wife since your diagnosis of prostate cancer. Please tell us how often you have responded this way **since your diagnosis with prostate cancer.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
	EXAMPLE: Since your diagnosis, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G1	Since your diagnosis, you've acted impatient with her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G2	Since your diagnosis, you've seemed angry or upset with her when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G3	Since your diagnosis you've complimented the way she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G4	Since your diagnosis, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G5	Since your diagnosis, you've made her wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G6	Since your diagnosis, you've made it comfortable for her to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G7	Since your diagnosis, you've avoided being around her when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G8	Since your diagnosis, you've given her the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	

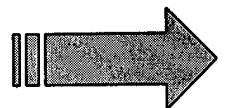
THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
G9	Since your diagnosis, you've shouted or yelled at her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G10	Since your diagnosis, you have made it a point to spend time with her when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G11	Since your diagnosis, you've not seemed to respect her feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G12	Since your diagnosis, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G13	Since your diagnosis, you've acted uncomfortable talking to her about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G14	Since your diagnosis, you've criticized the way she was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G15	Since your diagnosis, you have been affectionate with her when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G16	Since your diagnosis, you've acted less accepting of her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G17	Since your diagnosis, you've not been emotionally supportive of her when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	

The next questions concern your relationship with your wife since your diagnosis of prostate cancer. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: Since my diagnosis, I have not been able to turn to my wife for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree	
H1	Since my diagnosis, I have been able to depend on my wife to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H2	Since my diagnosis, I have not been able to turn to my wife for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H3	Since my diagnosis, my wife has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H4	Since my diagnosis, I have felt personally responsible for my wife's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H5	Since my diagnosis, I have not thought that my wife respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H6	Since my diagnosis, if something went wrong my wife would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H7	Since my diagnosis, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H8	Since my diagnosis, my wife has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H9	Since my diagnosis, my wife has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree	

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
H10	Since my diagnosis, my wife has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H11	Since my diagnosis, my wife has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H12	Since my diagnosis, I have lacked a feeling of intimacy with my wife.	Strongly Disagree	Disagree	Agree	Strongly Agree	

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE		
EXAMPLE: Accomplished less than you would like	<input checked="checked" type="radio"/> Yes	<input type="radio"/> No	
I11. Cut down on the amount of time you spent on work or other activities	Yes	No	
I12. Accomplished less than you would like	Yes	No	
I13. Were limited in the kind of work or other activities	Yes	No	
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No	

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE		
I15. Cut down on the amount of time you spent on work or other activities	Yes	No	
I16. Accomplished less than you would like	Yes	No	
I17. Didn't do work or other activities as carefully as usual	Yes	No	

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
The time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE			
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I35. In general, would you say your health is: Please circle your response.						
Excellent	Very Good	Good	Fair	Poor		
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.						
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.		

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.	
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J2. Which of the following best describes your urinary control **during the last 4 weeks**? Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.	
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J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.	
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How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem	
J5. Urine leakage interfering with your sexual activity.	No problem	Very small problem	Small problem	Moderate problem	Big problem	

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Please circle your response.

1-----2-----3-----4-----5
 No problem Very small problem Small problem Moderate problem Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS.**

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
Once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
Distress Distress Distress Distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
Times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
Problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good	
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good	
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good	

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.	
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J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.	
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J17. How often have you awakened in the morning or night with an erection? Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)	
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No	Yes, once	Yes, more than once
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1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

1-----2-----3-----4-----5
No Very Small Moderate Big
Problem small problem problem problem problem

1-----2-----3-----4-----5
Extremely Dissatisfied Dissatisfied Uncertain Satisfied Extremely satisfied

1. _____ No

2. _____ Yes If yes, please indicate which method you use.

_____ Viagra

_____ Injections

_____ Suppositories (MUSE)

_____ Vasomax

_____ Other Please specify: _____

Please answer the following questions related to your prostate cancer diagnosis.

K1. When did you **first** hear of the Prostate Specific Antigen (PSA) test or prostate blood test?

1. ☐ I have never heard of the PSA test.
2. ☐ I heard about it from the media (T.V., radio, newspaper, magazine).
3. ☐ I heard about it from my spouse.
4. ☐ I heard about it from my friends or relatives.
5. ☐ I heard about it from my primary care physician.
6. ☐ I heard about it from my urologist.
7. ☐ I heard about it today while in the clinic.

K2. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5
 None A little A moderate amount A lot A great deal

K3. Has a doctor ever talked to you about your PSA level? Please mark your response.

1. ☐ No (go to question K5).
2. ☐ Yes (go to question K4).
3. ☐ Don't know (go to question K5).

K4. How satisfied were you with the discussion that you had with your doctor about your PSA Level? Please circle your response.

1-----2-----3-----4-----5
 Not at all Slightly Moderately Quite a lot Completely
 Satisfied satisfied satisfied satisfied satisfied

K5. Do you know your last PSA value?

1. ☐ YES If Yes, please write it here: _____ PSA value (ng/ml)
2. ☐ NO If No, please mark one of the following options:
 - 2a. ☐ I don't remember my last PSA value.
 - 2b. ☐ I have never been told my PSA value.

K6. Do you know what different PSA levels mean? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Unsure

K7. How concerned were you when your doctor **first told you** that your PSA level was elevated or high? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite Extremely
Concerned concerned concerned concerned concerned

K8. Has a doctor ever talked to you about how your PSA level will be used to follow your treatment of prostate cancer? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Don't know.

K9. What do you think is the chance that you will have a recurrence of prostate cancer after your treatment? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance likely to happen

Did anyone assist you with the completion of this questionnaire?

No ☐ _____
Yes ☐ _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the second questionnaire one month after you begin your treatment for prostate cancer.

Spouse Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage paid envelope before your spouse's treatment for prostate cancer begins.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your husband, and views of your husband's illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / _____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. _____ Living with spouse or partner
2. _____ In a significant relationship, but not living together
3. _____ Not in a significant relationship

A9. What is your current marital status?

1. _____ Never married
2. _____ Married
3. _____ Separated
4. _____ Divorced
5. _____ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. _____ Your husband/wife
2. _____ Your mother
3. _____ Your father
4. _____ Your children 18 or under → How many? _____
5. _____ Your children over 18 → How many? _____
6. _____ Sister(s) → How many? _____
7. _____ Brother(s) → How many? _____
8. _____ Grandchildren → How many? _____
9. _____ Grandparent(s) → How many? _____
10. _____ Other relatives → How many? _____
11. _____ Other non-relatives → How many? _____
12. _____ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. _____ 0 - \$4,000
2. _____ \$4,001 - \$9,000
3. _____ \$9,001 - \$18,000
4. _____ \$18,001 - \$30,000
5. _____ \$30,001 - \$40,000
6. _____ \$40,001 - \$50,000
7. _____ \$50,001 - \$60,000
8. _____ Above \$60,000

A13. Altogether, how many people live on this income?

_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.		
Example: Asthma		No	Yes	Not At All	A Little	A Great Deal
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



The following statements are about your thoughts and feelings since your husband was diagnosed with prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment for my husband is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my husband's illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my husband's pain will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my husband's condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment for my husband is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	I do not know when to expect things will be done to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	My husband's symptoms continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE					
C11	I can predict how long my husband's illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C12	My husband's treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C13	It is difficult to know if the treatments or medications my husband is getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C14	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C15	Because of the unpredictability of my husband's illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C16	The course of my husband's illness keeps changing. He has good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C17	It's vague to me how I will manage my husband's care after he leaves the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C18	It is not clear what is going to happen to my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C19	I usually know if my husband is going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C20	The results of my husband's tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C21	The effectiveness of my husband's treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C22	It is difficult to determine how long it will be before I can care for my husband by myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C23	I can generally predict the course of my husband's illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	

THOUGHTS AND FEELINGS		CIRCLE RESPONSE					
C24	Because of the treatment, what my husband can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C25	I am certain they will not find anything else wrong with my husband.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C26	They have not given my husband a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C27	My husband's physical distress is predictable; I know when it is going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C28	My husband's diagnosis is definite and will not change.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C29	I can depend on the nurses to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C30	The seriousness of my husband's illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	
C31	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	

Please continue to the next page of the questionnaire.

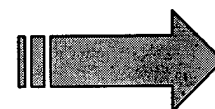


The following statements are about your sense of control over your life since your husband's prostate cancer diagnosis. Please circle the response that best describes how you think and feel about each statement.

SENSE OF CONTROL		CIRCLE RESPONSE				
Example: Most of my problems are due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	There is no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	The really good things that happen to me are mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	I am responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	I can do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	Most of my problems are due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	I have little control over the bad things that happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	My misfortunes are a result of the mistakes I have made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	I am responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best describes your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: Our marriage is strong.		Strongly Disagree	1-----2-----3-----4----- 5 -----6-----7 Strongly Agree
E1	We have a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	My relationship with my partner is very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	Our marriage is strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	My relationship with my partner makes me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	I really feel like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree
E6 On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage.			
1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very unhappy Happy Perfectly happy			



In the space below, please answer the following questions.

F1. Since your husband's diagnosis of prostate cancer, what has your husband said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way?

F2. Since your husband's diagnosis of prostate cancer, what have you wished that your husband had done or said to help you cope with his cancer that he did not do?

The statements below are possible reactions that you may have had towards your husband since his diagnosis of prostate cancer. Please tell us how often you have responded this way since his diagnosis.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: Since your husband's diagnosis, you seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	Since your husband's diagnosis, you've acted impatient with him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	Since your husband's diagnosis, you've seemed angry or upset with him when he needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	Since your husband's diagnosis, you've complimented the way he was coping with his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	Since your husband's diagnosis, you've seemed not to enjoy being around him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	Since your husband's diagnosis, you've made him wait a long time for help when he needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	Since your husband's diagnosis, you've made it comfortable for him to share with you how he was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	Since your husband's diagnosis, you've avoided being around him when he was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

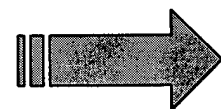
THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
G8	Since your husband's diagnosis, you've given him the idea you really did not want to talk about a problem he was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G9	Since your husband's diagnosis, you've shouted or yelled at him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G10	Since your husband's diagnosis, you've made it a point to spend time with him when you thought he was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G11	Since your husband's diagnosis, you haven't seemed to respect his feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G12	Since your husband's diagnosis, you've complained about his illness or about helping him with a task he found difficult to do by himself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G13	Since your husband's diagnosis, you've acted uncomfortable talking to him about his illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G14	Since your husband's diagnosis, you've criticized the way he was coping with his disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G15	Since your husband's diagnosis, you've been affectionate with him when you thought he needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G16	Since your husband's diagnosis, you've acted less accepting of him.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	
G17	Since your husband's diagnosis, you haven't been emotionally supportive of him when he expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way	

The next set of questions concern your relationship with your husband since his diagnosis of prostate cancer. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
Example: My husband does not view me as competent.		Strongly Disagree	Disagree	Agree	Strongly Agree	
H1	Since my husband's diagnosis, I have been able to depend on him to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H2	Since my husband's diagnosis, I have not been able to turn to him for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H3	Since my husband's diagnosis, he has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H4	Since my husband's diagnosis, I have felt personally responsible for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H5	Since my husband's diagnosis, I have not thought that he respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H6	Since my husband's diagnosis, if something went wrong he would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H7	Since my husband's diagnosis, I have had a close relationship with him that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H8	Since my husband's diagnosis, he has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H9	Since my husband's diagnosis, he has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree	

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
H10	Since my husband's diagnosis, he has not really relied on me for his well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H11	Since my husband's diagnosis, he has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	
H12	Since my husband's diagnosis, I have lacked a feeling of intimacy with him.	Strongly Disagree	Disagree	Agree	Strongly Agree	

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE		
EXAMPLE: Accomplished less than you would like	<input checked="checked" type="radio"/> Yes	<input type="radio"/> No	
I11. Cut down on the amount of time you spent on work or other activities	Yes	No	
I12. Accomplished less than you would like	Yes	No	
I13. Were limited in the kind of work or other activities	Yes	No	
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No	

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE		
I15. Cut down on the amount of time you spent on work or other activities	Yes	No	
I16. Accomplished less than you would like	Yes	No	
I17. Didn't do work or other activities as carefully as usual	Yes	No	

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
The time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE			
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.	
I35. In general, would you say your health is: Please circle your response.						
Excellent	Very Good	Good	Fair	Poor		
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.						
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.		

Please answer the following questions related to your husband's prostate cancer diagnosis.

K1. When did you **first** hear of the Prostate Specific Antigen (PSA) test or prostate blood test?

1. ☐ I have never heard of the PSA test.
2. ☐ I heard about it from the media (T.V., radio, newspaper, magazine).
3. ☐ I heard about it from my husband.
4. ☐ I heard about it from my friends or relatives.
5. ☐ I heard about it from my primary care physician.
6. ☐ I heard about it from my husband's urologist.
7. ☐ I heard about it today while in the clinic.

K2. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5
 None A little A moderate amount A lot A great deal

K3. Has a doctor ever talked to you about your husband's PSA level? Please mark your response.

1. ☐ No (go to question K5).
2. ☐ Yes (go to question K4).
3. ☐ Don't know (go to question K5).

K4. How satisfied were you with the discussion that you had with your husband's doctor about his PSA level? Please circle your response.

1-----2-----3-----4-----5
 Not at all Slightly Moderately Quite a lot Completely
 Satisfied satisfied satisfied satisfied satisfied

K5. Do you know your husband's last PSA value?

1. ☐ YES If Yes, please write it here: _____ PSA value (ng/ml)
2. ☐ NO If No, please mark one of the following options:
 - 2a. ☐ I don't remember his last PSA value.
 - 2b. ☐ I have never been told my husband's PSA value.

K6. Do you know what different PSA levels mean? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Unsure

K7. How concerned were you when your doctor **first told your husband** that his PSA level was elevated or high? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite Extremely
Concerned concerned concerned concerned concerned

K8. Has a doctor ever talked to you about how your husband's PSA level will be used to follow his treatment of prostate cancer? Please mark your response.

- 1. ☐ No
- 2. ☐ Yes
- 3. ☐ Don't know.

K9. What do you think is the chance that your husband will have a recurrence of prostate cancer after his treatment? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance likely to happen

Did anyone assist you with the completion of this questionnaire?

No ☐
Yes ☐ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the second questionnaire one month after your spouse begins his treatment for prostate cancer.

Appendix C

One Month Questionnaire

Patient with a Spouse One-Month Follow-Up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

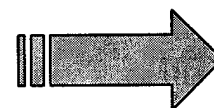
A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____



The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.** Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have impotence, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care now that I've left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment's side effects, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I am certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life **during the past month**. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors **during the past month.** Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE	
Example: During the past month, our marriage has been strong.		Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree <div style="text-align: center;"> </div>
E1	During the past month, we have had a good marriage.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree <div style="text-align: center;"> </div>
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree <div style="text-align: center;"> </div>
E3	During the past month, our marriage has been strong.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree <div style="text-align: center;"> </div>
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree <div style="text-align: center;"> </div>
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree	1-----2-----3-----4-----5-----6-----7 Strongly Agree <div style="text-align: center;"> </div>
E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u> . Please circle the number that best represents your response.			
<div style="text-align: center;"> 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 </div> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> Very unhappy Happy Perfectly happy </div>			



In the space below, please answer the following questions.

F1. During the past month, what has your wife said or done that you experienced as most annoying or That upset you, made you angry, or just somehow rubbed you the wrong way?

F2. During the past month, what have you wished that your wife had done or said to help you cope with recovering from cancer that she did not do?

The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way during the past month.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with her when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made her wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for her to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around her when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given her the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

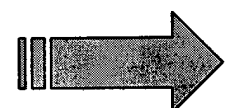
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with her when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect her feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to her about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way she was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with her when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of her when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your wife during the past month. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my wife for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my wife to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my wife for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my wife has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my wife's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my wife respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my wife would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my wife has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my wife has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H10	During the past month, my wife has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my wife.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	Yes	No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of the time Most of the time Some of the time A little of the time None of the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago, how would you rate your health in general now? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.
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J2. Which of the following best describes your urinary control **during the last 4 weeks**? Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.
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J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.
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How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem
J5. Urine leakage interfering with your sexual activity.	No problem	Very small problem	Small problem	Moderate problem	Big problem

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Please circle your response.

1-----2-----3-----4-----5
 No problem Very Small problem Small problem Moderate problem Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS.**

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the Last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
distress distress distress distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.
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J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.
--	---	---	---	--

J17. How often have you awakened in the morning or night with an erection? Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)
-------	------------------------------------	-------------------------------------	----------------------------------	--

J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response.

No

Yes, once

Yes, more than once

J19. Overall, how would you rate your ability to function sexually during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
No Very Small Moderate Big
problem small problem problem problem problem

J21. Overall, how satisfied are you with the treatment you received for your prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Extremely Dissatisfied Uncertain Satisfied Extremely
dissatisfied satisfied

J22a. Have you had erections since your treatment for prostate cancer?

1. _____ No If no please go to question K1.
2. _____ Yes If yes, please go to question J22b.

J22b. Do your erections require assistance? Please mark your response.

1. _____ No If no, please go to question K1.
2. _____ Yes If yes, please indicate which method you use.

☐ Viagra
☐ Vasomax
☐ Penile Injections
☐ Urethral Suppositories (MUSE)
☐ Vacuum Device
☐ Constriction Ring
☐ Other Please specify: _____

Please answer the following questions related to your prostate cancer diagnosis.

K1. How much do you know about how the PSA test is used to detect prostate cancer? Please circle your response.

1-----2-----3-----4-----5 None
A little A moderate A lot A great deal
amount

K2. Did a doctor ever talk to you about your PSA level after surgery? Please mark your response.

1. ____ Yes (**Go to K3a**)

K3a. How satisfied were you with the discussion that you had with your doctor about your PSA level after surgery? Please circle your response; then go to question K4.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a lot Completely
satisfied satisfied satisfied satisfied satisfied

2. ____ No (**Go to K3b**)

K3b. Do you wish you'd had the opportunity to talk to your doctor about your PSA level after surgery? ____ YES ____ NO

3. ____ Don't know

K4. Do you know your last PSA value?

1. ____ YES If Yes, please write it here: _____ PSA value (ng/ml)

2. ____ NO If No, please mark one of the following options:

2a. _____ I don't remember my last PSA value.

2b. _____ I have never been told my PSA value.

K5. Do you know what different PSA levels mean? Please mark your response.

1. ☐ No
2. ☐ Yes
3. ☐ Unsure

K6. Has a doctor ever talked to you about how your PSA level will be used to follow your treatment of prostate cancer? Please mark your response.

1. ☐ No
2. ☐ Yes
3. ☐ Don't know

K7. What do you think is the chance that you will have a recurrence of prostate cancer after your treatment? Please circle your response.

1-----2-----3-----4-----5-----6-----7						
No chance	Very unlikely	Unlikely	Moderate chance	Likely	Very likely	Certain to happen

K8. How worried are you that you will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5				
Not at all worried	Slightly worried	Moderately worried	Very worried	Extremely worried

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated
Or underestimated
its importance
You saw things
in the right
proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often
Very seldom
or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often
Very seldom
or never

Q1. Did anyone assist you with the completion of this survey?

No _____

Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the third questionnaire six months from your treatment and/or management initiation date.

Appendix D

Six Month Questionnaire

Patient with a Spouse Six-Month Follow-Up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week of receipt.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

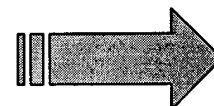
A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

Alternate Phone Number: (____) _____ - _____



The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each Treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have impotence, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care now that I've left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment's side effects, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I am certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life during the past month. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE
Example: During the past month, our marriage has been strong.		Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good marriage.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our marriage has been strong.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
<p>E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u>. Please circle the number that best represents your response.</p> <p>1-----2-----3-----4-----5-----6-----7-----8-----9-----10</p> <p>Very unhappy Happy Perfectly happy</p>		

In the space below, please answer the following questions.

F1. During the past month, what has your wife said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you the wrong way in regards to how you are coping with prostate cancer?

F2. During the past month, what have you wished that your wife had done or said to help you cope with recovering from cancer that she did not do?

The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way during the past month.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with her when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made her wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for her to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around her when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given her the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

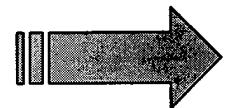
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with her when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect her feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to her about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way she was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with her when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of her when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your wife during the past month. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my wife for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my wife to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my wife for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my wife has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my wife's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my wife respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my wife would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my wife has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my wife has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H10	During the past month, my wife has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my wife.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please
 circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	No, not limited at all

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	<input checked="" type="radio"/> Yes	<input type="radio"/> No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
the time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS.**

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.
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J2. Which of the following best describes your urinary control **during the last 4 weeks?** Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.
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J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks?** Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.
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How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem
J5. Urine leakage interfering with your sexual activity.	No problem	Very small problem	Small problem	Moderate problem	Big problem

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks?** Please circle your response.

1-----2-----3-----4-----5
 No problem Very small problem Small problem Moderate problem Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS.**

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks? Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
distress distress distress distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.
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J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.
--	---	---	---	--

J17. How often have you awakened in the morning or night with an erection? Please circle your response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)
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No	Yes, once	Yes, more than once
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1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

1-----2-----3-----4-----5
No Very Small Moderate Big
problem small problem problem problem problem

1-----2-----3-----4-----5
Extremely Dissatisfied Uncertain Satisfied Extremely
dissatisfied satisfied

1. _____ No If no please go to question K1.
2. _____ Yes If yes, please go to question J22b.

1. _____ No If no, please go to question K1.
2. _____ Yes If yes, please indicate which method you use.

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Please answer the following questions related to your prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

K1. Do you know why the PSA level is measured after surgery?

1 _____ NO (if no, please go to K2)

2 _____ YES (If yes, please answer K1a)

K1a. In the space below please explain briefly why you think the PSA is measured after surgery.

K2. Do you know what it means to have a detectable PSA level after surgery?

1 _____ NO (if no, please go to K3)

2 _____ YES (if yes, please answer K2a)

K2a. Please explain briefly what you think it means to have a detectable PSA level after surgery.

K3. Do you think having a detectable PSA level after surgery means that prostate cancer is still present?

1 _____ NO

2 _____ YES

3 _____ Don't know

K4. How many PSA tests have you had since surgery? _____ (Number of tests)

K5. When was your last PSA test? ____/____/____ (Date)

K6. Do you know your last PSA value?

1 ____ NO (if no, please mark one of the following options and go to K7.)

A. ____ I don't remember my last PSA value.

B. ____ I have never been told my PSA value.

2 ____ YES (if yes, please write it here: _____ PSA value (ng/ml) **and go to K6a.**)

K6a. How reassured were you by the results of your last PSA test? Please circle your response

1-----	2-----	3-----	4-----	5-----
Not at all reassured	Slightly reassured	Moderately reassured	Very reassured	Extremely reassured

K7. Was the value of your last PSA test "not detectable" (sometimes called "zero" or "less than zero")?

1 ____ NO (if no, please go to K8)

2 ____ Don't know (please go to K8)

3 ____ I have not had a PSA test since I had my surgery for prostate cancer. (go to K8)

4 ____ YES (if yes, please go to K7a.)

K7a. How reassuring is it to you that your last PSA value was "not detectable" (sometimes called "zero" or "less than zero")? Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all reassuring	Slightly reassuring	Moderately reassuring	Very reassuring	Extremely reassuring

K8. Do you wish you'd had the opportunity to talk more to your doctor about what the results of your last PSA test mean?

1 ____ YES

2 ____ NO

3 ____ Don't know

K9. How worried are you about the results of your most recent PSA test(s)?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K10. How worried are you about the actual number of PSA tests you've had since surgery?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K11. Do you feel you've had the right amount of PSA tests since your surgery?

- 1 _____ Should have had fewer (please go to K12)
2 _____ Number of tests is about right (please go to K12)
3 _____ Should have had more (if more, please go to K11a.)

K11a. How many more tests do you think you should have had? _____.

K12. How long after surgery (months or years) would you want to continue having your PSA level measured? Please enter your response in the appropriate space below.

_____ Months OR _____ Years

K13. Has a doctor ever talked with you about how the PSA test will be used to help monitor Your prostate cancer?

- 1 _____ NO (If no, go to K14)
2 _____ YES (If yes, go to K13a.)

K13a. How satisfied have you been with your doctor's explanations about why the PSA test is used to help follow you after your surgery for prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Completely
satisfied satisfied satisfied satisfied satisfied

K14. What do you think is the chance that you will have a recurrence of prostate cancer after your surgery? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance chance likely likely to happen

K15. How worried are you that you will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
Worried worried worried worried worried

K16. **Before your surgery**, did you join a prostate cancer support group?

1 _____ NO (if no, please go to K17.)

2 _____ YES (if yes, please go to K16a.)

K16a. About how often did you attend prostate cancer support group meetings prior to surgery?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month

K17. **After your surgery**, did you join a prostate cancer support group?

1 _____ NO

2 _____ YES (if yes, please go to K17a)

K17a. About how often did you attend prostate cancer support group meetings?

1 _____ Several times a week

2 _____ About once a week

3 _____ About twice a month

4 _____ About once a month

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____

Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the fourth questionnaire twelve months from your treatment and/or management initiation date.

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Appendix E

Twelve Month

Questionnaire

Patient with a Spouse Twelve-Month Follow-Up Questionnaire

WELCOME!

This is the beginning of the questionnaire. We would like to thank you, in advance, for the time and thought you invest in filling it out. Please complete and return this survey in the postage-paid envelope within 1 week of receipt.

INSTRUCTIONS: In the following pages, you will be asked several questions about your health, well-being, quality of life, perceptions of support that you give and receive from your spouse, and views of your illness. Please try to answer each question. While you complete the questionnaire, please do not talk about the questions or answers with anyone. All your responses will be kept strictly confidential, and will not be seen by your spouse. Should you have any questions, please call Jill Smith at (919) 956-5644. In advance, thank you for your time and efforts.

We will begin by asking you some questions about your background.

GENERAL BACKGROUND INFORMATION - PLEASE PRINT.

A1. Today's date: _____ / _____ / _____
Month Day Year

A2. Name: _____

A3. Home Address: _____ Apt. # _____
Street

City State Zip Code

A4. Home Phone Number: (____) _____ - _____

A5. Date of Birth: _____ / _____ / _____
Month Day Year

A6. What is your highest level of education? (Put a checkmark by the answer.)

1. _____ Grade school
2. _____ Some high school
3. _____ High school graduate
4. _____ Some college
5. _____ College graduate
6. _____ Graduate education

A7. Which of the following best describes your racial or ethnic background?

1. _____ White, not of Hispanic origin
2. _____ Black or African-American, not of Hispanic origin
3. _____ Hispanic
4. _____ American Indian/Alaskan native
5. _____ Asian/Pacific Islander
6. _____ Hawaiian native
7. _____ Other (please specify). _____

A8. Which of the following best describes your current relationship?

1. ☐ Living with spouse or partner
2. ☐ In a significant relationship, but not living together
3. ☐ Not in a significant relationship

A9. What is your current marital status?

1. ☐ Never married
2. ☐ Married
3. ☐ Separated
4. ☐ Divorced
5. ☐ Widowed

A10. How long have you been married/separated/divorced/widowed? _____ years

A11. Who else lives in your household besides yourself? (Please check all that apply.)

1. ☐ Your husband/wife
2. ☐ Your mother
3. ☐ Your father
4. ☐ Your children 18 or under → How many? _____
5. ☐ Your children over 18 → How many? _____
6. ☐ Sister(s) → How many? _____
7. ☐ Brother(s) → How many? _____
8. ☐ Grandchildren → How many? _____
9. ☐ Grandparent(s) → How many? _____
10. ☐ Other relatives → How many? _____
11. ☐ Other non-relatives → How many? _____
12. ☐ I live by myself.

A12. Here are several broad income ranges. Please select the range that most closely approximates your yearly household income, before taxes, from all sources, including social security.

1. ☐ 0 - \$4,000
2. ☐ \$4,001 - \$9,000
3. ☐ \$9,001 - \$18,000
4. ☐ \$18,001 - \$30,000
5. ☐ \$30,001 - \$40,000
6. ☐ \$40,001 - \$50,000
7. ☐ \$50,001 - \$60,000
8. ☐ Above \$60,000

A13. Altogether, how many people live on this income?

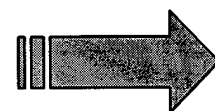
_____ People.

Do you have any of the following illnesses or conditions at the present time?

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.		
Example: Asthma		No	<input checked="" type="radio"/> Yes	Not At All	<input checked="" type="radio"/> A Little	A Great Deal
B1	Anemia	No	Yes	Not At All	A Little	A Great Deal
B2	Arthritis or rheumatism	No	Yes	Not At All	A Little	A Great Deal
B3	Asthma	No	Yes	Not At All	A Little	A Great Deal
B4	Cancer or leukemia	No	Yes	Not At All	A Little	A Great Deal
B5	Circulation trouble in arms, legs, or feet	No	Yes	Not At All	A Little	A Great Deal
B6	Depression, anxiety or emotional problems	No	Yes	Not At All	A Little	A Great Deal
B7	Diabetes	No	Yes	Not At All	A Little	A Great Deal
B8	Effects of Polio	No	Yes	Not At All	A Little	A Great Deal
B9	Effects of stroke	No	Yes	Not At All	A Little	A Great Deal
B10	Emphysema or chronic bronchitis	No	Yes	Not At All	A Little	A Great Deal
B11	Epilepsy/seizures	No	Yes	Not At All	A Little	A Great Deal
B12	Glaucoma	No	Yes	Not At All	A Little	A Great Deal
B13	Heart Disease	No	Yes	Not At All	A Little	A Great Deal
B14	High blood pressure (greater than 140/90)	No	Yes	Not At All	A Little	A Great Deal
B15	Kidney disease	No	Yes	Not At All	A Little	A Great Deal
B16	Liver disease	No	Yes	Not At All	A Little	A Great Deal
B17	Multiple Sclerosis	No	Yes	Not At All	A Little	A Great Deal

ILLNESS / CONDITION		Circle No or Yes		If YES, circle how much the illness interferes with your daily activities.			
B18	Stomach or intestinal disorders, gall bladder problems, or irritable bowel syndrome	No	Yes	Not At All	A Little	A Great Deal	
B19	Other urinary tract disorders (including prostate trouble)	No	Yes	Not At All	A Little	A Great Deal	
B20	Parkinson's Disease	No	Yes	Not At All	A Little	A Great Deal	
B21	Severe memory problems such as Alzheimer's or other dementing illness	No	Yes	Not At All	A Little	A Great Deal	
B22	Skin disorders such as pressure sores, leg ulcers, or severe burns.	No	Yes	Not At All	A Little	A Great Deal	
B23	Thyroid or other glandular disorders	No	Yes	Not At All	A Little	A Great Deal	
B24	Tuberculosis	No	Yes	Not at All	A Little	A Great Deal	
B25	Stomach Ulcers	No	Yes	Not at All	A Little	A Great Deal	
B26	Leg Amputation(s)	No	Yes	Not at All	A Little	A Great Deal	

Please continue to the next page of the questionnaire.



The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer. Please circle the statement that best describes your thoughts and feelings. Please respond to every statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
EXAMPLE: The purpose of each Treatment is clear to me.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C1	I do not know what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C2	I have a lot of questions without answers.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C3	I am unsure if my illness is getting better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C4	It is unclear how bad my incontinence will be.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C5	The explanations they give about my condition seem hazy to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C6	The purpose of each treatment is clear to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C7	When I have impotence, I know what this means about my condition.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C8	I do not know when to expect things will be done to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C9	My symptoms/side effects continue to change unpredictably.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C10	I understand everything explained to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C11	The doctors say things to me that could have many meanings.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings since beginning your treatment for and/or management of prostate cancer.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C12	I can predict how long my illness will last.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C13	My treatment is too complex to figure out.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C14	It is difficult to know if the treatments or medications I am getting are helping.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C15	There are so many different types of staff, it is unclear who is responsible for what.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C16	Because of the unpredictability of my illness, I cannot plan for the future.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C17	The course of my illness keeps changing. I have good days and bad days.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C18	It is vague to me how I will manage my care now that I've left the hospital.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C19	I have been given many differing opinions about what is wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C20	It is not clear what is going to happen to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C21	I usually know if I am going to have a good or bad day.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C22	The results of my tests are inconsistent.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C23	The effectiveness of my treatment is undetermined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your thoughts and feelings **since beginning your treatment for and/or management of prostate cancer.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE				
C24	It is difficult to determine how long it will be before I can care for myself.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C25	I can generally predict the course of my illness.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C26	Because of the treatment's side effects, what I can do and cannot do keeps changing.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C27	I am certain they will not find anything else wrong with me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C28	The treatment I am receiving has a known probability of success.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C29	They have not given me a specific diagnosis.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C30	My incontinence and impotence are predictable; I know when they are going to get better or worse.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C31	I can depend on the clinic staff to be there when I need them.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C32	The seriousness of my illness has been determined.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
C33	The doctors and nurses use everyday language so I can understand what they are saying.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The following statements are about your sense of control over your life during the past month. Please circle the response that best describes how you have thought and felt during the past four weeks.

SENSE OF CONTROL		CIRCLE RESPONSE				
EXAMPLE: During the past month, most of my problems were due to bad breaks.		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D1	During the past month, there was no sense in planning a lot. If something is going to happen, it will.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D2	During the past month, the really good things that happened to me were mostly luck.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D3	During the past month, I was responsible for my own successes.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D4	During the past month, I could do just about anything I really set my mind to.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D5	During the past month, most of my problems were due to bad breaks.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D6	During the past month, I had little control over the bad things that happened to me.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D7	During the past month, my misfortunes were a result of the mistakes I made.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
D8	During the past month, I was responsible for my failures.	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

The next questions ask about marital attitudes and behaviors **during the past month**. Answer all questions as honestly as possible. Answer all questions with your partner in mind unless directed otherwise. **Please answer the questions without talking to your partner.** Your partner should not see or help with the answers. Circle the number from 1 to 7 that best reflects your thoughts and feelings about each statement.

ATTITUDES AND BEHAVIORS		CIRCLE RESPONSE
Example: During the past month, our marriage has been strong.		Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E1	During the past month, we have had a good marriage.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E2	During the past month, my relationship with my partner has been very stable.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E3	During the past month, our marriage has been strong.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E4	During the past month, my relationship with my partner has made me happy.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
E5	During the past month, I have really felt like part of a team with my partner.	Strongly Disagree 1-----2-----3-----4-----5-----6-----7 Strongly Agree
<p>E6. On the scale below, circle the number from 1-10 that best describes the degree of happiness, everything considered, in your marriage <u>during the past month</u>. Please circle the number that best represents your response.</p> <p>1-----2-----3-----4-----5-----6-----7-----8-----9-----10</p> <p>Very unhappy Happy Perfectly happy</p>		

In the space below, please answer the following questions.

F1. During the past month, what has your wife said or done that you experienced as most annoying or That upset you, made you angry, or just somehow rubbed you the wrong way in regards to how you Are coping with prostate cancer?

F2. During the past month, what have you wished that your wife had done or said to help you cope with recovering from cancer that she did not do?

The statements below are possible reactions that you may have had towards your wife. Please tell us how often you have responded this way **during the past month.**

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
	EXAMPLE: During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G1	During the past month, you've acted impatient with her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G2	During the past month, you've seemed angry or upset with her when she needed assistance.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G3	During the past month, you've complimented the way she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G4	During the past month, you've seemed not to enjoy being around her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G5	During the past month, you've made her wait a long time for help when she needed it.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G6	During the past month, you've made it comfortable for her to share with you how she was feeling.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G7	During the past month, you've avoided being around her when she was not feeling well.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G8	During the past month, you've given her the idea you really did not want to talk about a problem she was having.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

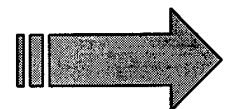
THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
G9	During the past month, you've shouted or yelled at her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G10	During the past month, you've made it a point to spend time with her when you thought she was feeling low.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G11	During the past month, you've not seemed to respect her feelings.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G12	During the past month, you've complained about any medical problems she might have, or about helping her with a task she found difficult to do by herself.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G13	During the past month, you've acted uncomfortable talking to her about how she was coping with your illness.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G14	During the past month, you've criticized the way she was coping with your disease and/or its treatment.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G15	During the past month, you've been affectionate with her when you thought she needed support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G16	During the past month, you've acted less accepting of her.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way
G17	During the past month, you've not been emotionally supportive of her when she expected some support.	Never responded this way	Rarely responded this way	Sometimes responded this way	Often responded this way

The following questions concern your relationship with your wife **during the past month**. Please circle the response that best describes your thoughts and feelings about each statement.

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
EXAMPLE: During the past month, I have not been able to turn to my wife for guidance in times of stress.		Strongly Disagree	Disagree	Agree	Strongly Agree
H1	During the past month, I have been able to depend on my wife to help me if I really need it.	Strongly Disagree	Disagree	Agree	Strongly Agree
H2	During the past month, I have not been able to turn to my wife for guidance in times of stress.	Strongly Disagree	Disagree	Agree	Strongly Agree
H3	During the past month, my wife has enjoyed the same social activities I do.	Strongly Disagree	Disagree	Agree	Strongly Agree
H4	During the past month, I have felt personally responsible for my wife's well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H5	During the past month, I have not thought that my wife respected my skills and abilities.	Strongly Disagree	Disagree	Agree	Strongly Agree
H6	During the past month, if something went wrong my wife would not come to my assistance.	Strongly Disagree	Disagree	Agree	Strongly Agree
H7	During the past month, I have had a close relationship with my wife that provides me with a sense of emotional security and well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H8	During the past month, my wife has recognized my competence and skill.	Strongly Disagree	Disagree	Agree	Strongly Agree
H9	During the past month, my wife has not shared my interests and concerns.	Strongly Disagree	Disagree	Agree	Strongly Agree

THOUGHTS AND FEELINGS		CIRCLE RESPONSE			
H10	During the past month, my wife has not really relied on me for her well-being.	Strongly Disagree	Disagree	Agree	Strongly Agree
H11	During the past month, my wife has been a trustworthy person I could turn to for advice if I were having problems.	Strongly Disagree	Disagree	Agree	Strongly Agree
H12	During the past month, I have lacked a feeling of intimacy with my wife.	Strongly Disagree	Disagree	Agree	Strongly Agree

Please continue to the next page of the questionnaire.



The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much? Please circle your response.

ACTIVITIES	CIRCLE RESPONSE		
EXAMPLE: Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I1. Vigorous activities , such as running, lifting heavy objects, or participating in strenuous sports	Yes, limited a lot	Yes, limited a little	No, not limited at all
I2. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	Yes, limited a lot	Yes, limited a little	No, not limited at all
I3. Lifting or carrying groceries	Yes, limited a lot	Yes, limited a little	No, not limited at all
I4. Climbing several flights of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I5. Climbing one flight of stairs	Yes, limited a lot	Yes, limited a little	No, not limited at all
I6. Bending, kneeling, or stooping	Yes, limited a lot	Yes, limited a little	No, not limited at all
I7. Walking more than a mile	Yes, limited a lot	Yes, limited a little	No, not limited at all
I8. Walking several blocks	Yes, limited a lot	Yes, limited a little	No, not limited at all
I9. Walking one block	Yes, limited a lot	Yes, limited a little	No, not limited at all
I10. Bathing or dressing yourself	Yes, limited a lot	Yes, limited a little	

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**? Please circle YES or NO for each question.

PROBLEMS AS A RESULT OF PHYSICAL HEALTH	CIRCLE RESPONSE	
EXAMPLE: Accomplished less than you would like	<input checked="" type="radio"/> Yes	<input type="radio"/> No
I11. Cut down on the amount of time you spent on work or other activities	Yes	No
I12. Accomplished less than you would like	Yes	No
I13. Were limited in the kind of work or other activities	Yes	No
I14. Had difficulty performing the work or other activities (for example, it took extra effort)	Yes	No

During the **PAST 4 WEEKS**, have you had any of the following problems with your work or other daily activities as a result of any **EMOTIONAL PROBLEMS**, such as feeling depressed or anxious? Please circle YES or NO for each question.

EMOTIONAL PROBLEMS	CIRCLE RESPONSE	
I15. Cut down on the amount of time you spent on work or other activities	Yes	No
I16. Accomplished less than you would like	Yes	No
I17. Didn't do work or other activities as carefully as usual	Yes	No

These questions are about how you feel and how things have been with you **during the PAST 4 WEEKS**. For each question, please circle the answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks** ...

FEELINGS		CIRCLE RESPONSE					
EXAMPLE: Have you felt calm and peaceful?		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I18.	Did you feel full of pep?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I19.	Have you been a very nervous person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I20.	Have you felt so down in the dumps that nothing could cheer you up?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I21.	Have you felt calm and peaceful?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I22.	Did you have a lot of energy?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I23.	Have you felt downhearted and blue?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I24.	Did you feel worn out?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I25.	Have you been a happy person?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
I26.	Did you feel tired?	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time

I27. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? Please circle your response.

1-----2-----3-----4-----5
All of Most of Some of A little of None of
the time the time the time the time the time

I28. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely

I29. How much **bodily** pain have you had during the **past 4 weeks**? Please circle your response.

1-----2-----3-----4-----5-----6
None Very mild Mild Moderate Severe Very severe

I30. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Quite a bit Extremely



Please choose the answer that best describes how true or false each of the following statements is for you. **Circle one item on each line.**

STATEMENT			CIRCLE RESPONSE		
EXAMPLE: I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I31. I seem to get sick a little easier than other people.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I32. I am as healthy as anyone I know.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I33. I expect my health to get worse.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I34. My health is excellent.	Definitely true.	Mostly true.	Not sure.	Mostly false.	Definitely false.
I35. In general, would you say your health is: Please circle your response.					
Excellent	Very Good	Good	Fair	Poor	
I36. Compared to one year ago , how would you rate your health in general now ? Please circle your response.					
Much better now than one year ago.	Somewhat better now than one year ago.	About the same.	Somewhat worse now than one year ago.	Much worse now than one year ago.	

URINARY FUNCTION: This section is about your urinary habits. Please consider **ONLY THE LAST 4 WEEKS**.

J1. Over the past 4 weeks, how often have you leaked urine? Please circle your response.

Every day	About once a week.	Less than once a week.	Not at all.
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J2. Which of the following best describes your urinary control **during the last 4 weeks**? Please circle your response.

No control whatsoever.	Frequent dribbling.	Occasional dribbling.	Total control.
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J3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Please circle your response.

3 or more pads per day.	1-2 pads per day.	No pads.
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How big a problem, if any, has each of the following been for you? Please circle your response.

J4. Dripping urine or wetting your pants.	No problem	Very small problem	Small problem	Moderate problem	Big problem
J5. Urine leakage interfering with your sexual activity	No problem	Very small problem	Small problem	Moderate problem	Big problem

J6. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Please circle your response.

1-----2-----3-----4-----5
 No problem Very small problem Small problem Moderate problem Big problem

BOWEL HABITS: This section is about your bowel habits and abdominal pain.
Please consider **ONLY THE LAST 4 WEEKS.**

J7. How often have you had rectal urgency (felt like you had to pass stool, but did not) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
More than About once More than once About once Rarely
once a day a day a week a week or never

J8. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Please circle your response.

1-----2-----3-----4-----5
Never Rarely About half Usually Always
the time

J9. How much distress have your bowel movements caused you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4
Severe Moderate Little No
distress distress distress distress

J10. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5-----6
Several About once Several About once About once Rarely
times a day a day times a week a week this month or never

J11. Overall, how big a problem has your bowel habits been for you during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Big Moderate Small Very small No
problem problem problem problem problem

SEXUAL FUNCTION: The next section is about your sexual function and sexual satisfaction. Many of the questions are very personal, but they will help us understand the important issues that you face every day. Remember, **YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY.** Please answer honestly about **THE LAST 4 WEEKS ONLY.**

How has each of the following been for you? Please circle your response.

J12. Your level of sexual Desire?	Very poor	Poor	Fair	Good	Very good
J13. Your ability to have an Erection?	Very poor	Poor	Fair	Good	Very good
J14. Your ability to reach Orgasm (climax)?	Very poor	Poor	Fair	Good	Very good

J15. How would you describe the usual **QUALITY** of your erections? Please circle your response.

None at all.	Not firm enough for any sexual activity.	Firm enough for masturbation and foreplay only.	Firm enough for intercourse.
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J16. How would you describe the **FREQUENCY** of your erections? Please circle your response.

I NEVER had an erection when I wanted one.	I had an erection LESS THAN HALF the time I wanted one.	I had an erection ABOUT HALF the time I wanted one.	I had an erection MORE THAN HALF the time I wanted one.	I had an erection WHENEVER I wanted one.
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J17. How often have you awakened in the morning or night with an erection? Please circle your Response.

Never	Seldom (less than 25% of the time)	Not often (less than half the time)	Often (more than half the time).	Very often (more than 75% of the time)
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J18. During the last 4 weeks, did you have vaginal or anal intercourse? Please circle your response.

Yes, once

Yes, more than once

J19. Overall, how would you rate your ability to function sexually during the last 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
Very poor Poor Fair Good Very good

J20. Overall, how big a problem has your sexual function been for you during the past 4 weeks?
Please circle your response.

1-----2-----3-----4-----5
No Very Small Moderate Big
Problem small problem problem problem problem

J21. Overall, how satisfied are you with the treatment you received for your prostate cancer?
Please circle your response.

1-----2-----3-----4-----5
 Extremely Dissatisfied Dissatisfied Uncertain Satisfied Extremely satisfied

J22a. Have you had erections since your treatment for prostate cancer?

1. ☐ No. If no, please go to question K1.

1. ☐ No If no please go to question K1.
2. ☐ Yes If yes, please go to question J22b.

J22b. Do your erections require assistance? Please mark your

1. ☐ No If no, please go to question K1.

2. _____ Yes If yes, please indicate which method you use.

_____ Viagra

_____ Vasomax

☐ Vasomax
☐ Penile Injections
☐ Urethral Suppositories (MUSE)
☐ Vacuum Device

☐ Vacuum Device
☐ Constriction Ring
☐ Other Please specify: _____

Please answer the following questions related to your prostate cancer and the PSA (Prostate Specific Antigen) test.

The PSA is a relatively new test, and there is much to learn about how its use affects patients. While answering the questions below, if you are unsure of any words or terms, please make your best guess.

K1. Do you know why the PSA level is measured after surgery?

1 _____ NO (if no, please go to K2)

2 _____ YES (If yes, please answer K1a)

K1a. In the space below please explain briefly why you think the PSA is measured after surgery.

K2. Do you know what it means to have a detectable PSA level after surgery?

1 _____ NO (if no, please go to K3)

2 _____ YES (if yes, please answer K2a)

K2a. Please explain briefly what you think it means to have a detectable PSA level after surgery.

K3. Do you think having a detectable PSA level after surgery means that prostate cancer is still present?

1 _____ NO

2 _____ YES

3 _____ Don't know

K4. How many PSA tests have you had since surgery? _____ (Number of tests)

K5. When was your last PSA test? ____/____/____ (Date)

K6. Do you know your last PSA value?

1 ____ NO (if no, please mark one of the following options and go to K7.)

A. ____ I don't remember my last PSA value.

B. ____ I have never been told my PSA value.

2 ____ YES (if yes, please write it here: _____ PSA value (ng/ml) **and go to K6a.**)

K6a. How reassured were you by the results of your last PSA test? Please circle your response

1-----	2-----	3-----	4-----	5-----
Not at all reassured	Slightly reassured	Moderately reassured	Very reassured	Extremely reassured

K7. Was the value of your last PSA test "not detectable" (sometimes called "zero" or "less than zero")?

1 ____ NO (if no, please go to K8)

2 ____ Don't know (please go to K8)

3 ____ I have not had a PSA test since I had my surgery for prostate cancer. (go to K8)

4 ____ YES (if yes, please go to K7a.)

K7a. How reassuring is it to you that your last PSA value was "not detectable" (sometimes called "zero" or "less than zero")? Please circle your response.

1-----	2-----	3-----	4-----	5-----
Not at all reassuring	Slightly reassuring	Moderately reassuring	Very reassuring	Extremely reassuring

K8. Do you wish you'd had the opportunity to talk more to your doctor about what the results of your last PSA test mean?

1 ____ YES

2 ____ NO

3 ____ Don't know

K9. How worried are you about the results of your most recent PSA test(s)?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K10. How worried are you about the actual number of PSA tests you've had since surgery?
Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
worried worried worried worried worried

K11. Do you feel you've had the right amount of PSA tests since your surgery?

- 1 _____ Should have had fewer (please go to K12)
2 _____ Number of tests is about right (please go to K12)
3 _____ Should have had more (if more, please go to K11a.)

K11a. How many more tests do you think you should have had? _____.

K12. How long after surgery (months or years) would you want to continue having your PSA level measured? Please enter your response in the appropriate space below.

_____ Months OR _____ Years

K13. Has a doctor ever talked with you about how the PSA test will be used to help monitor Your prostate cancer?

- 1 _____ NO (If no, go to K14)
2 _____ YES (If yes, go to K13a.)

K13a. How satisfied have you been with your doctor's explanations about why the PSA test is used to help follow you after your surgery for prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Completely
satisfied satisfied satisfied satisfied satisfied

K14. What do you think is the chance that you will have a recurrence of prostate cancer after your surgery? Please circle your response.

1-----2-----3-----4-----5-----6-----7
No Very Unlikely Moderate Likely Very Certain
chance unlikely chance to happen

K15. How worried are you that you will have a recurrence of prostate cancer? Please circle your response.

1-----2-----3-----4-----5
Not at all Slightly Moderately Very Extremely
Worried worried worried worried worried

K16. **Before your surgery**, did you join a prostate cancer support group?

- 1 _____ NO (if no, please go to K17.)
2 _____ YES (if yes, please go to K16a.)

K16a. About how often did you attend prostate cancer support group meetings prior to surgery?

- 1 _____ Several times a week
2 _____ About once a week
3 _____ About twice a month
4 _____ About once a month

K17. **After your surgery**, did you join a prostate cancer support group?

- 1 _____ NO
2 _____ YES (if yes, please go to K17a)

K17a. About how often did you attend prostate cancer support group meetings?

- 1 _____ Several times a week
2 _____ About once a week
3 _____ About twice a month
4 _____ About once a month

Please tell us how strongly you agree or disagree with each statement below by circling the response that best describes your feelings.

EXAMPLE: I feel that my efforts are noticed and rewarded.		Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L1	I feel that I get what I am entitled to in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L2	I feel that my efforts are noticed and rewarded.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L3	I feel that people treat me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L4	I feel that I earn the rewards and punishments I get.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L5	I feel that when I meet with misfortune, I have brought it upon myself.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L6	I feel that I get what I deserve in life.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L7	I feel that people treat me with the respect that I deserve.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L8	I feel the world treats me fairly.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree
L9	I basically believe the world is a fair place.	Strongly Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Strongly Agree

Below are questions about various aspects of our lives. Each question has seven possible answers. Please circle the number that best describes how you feel.

EXAMPLE: Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M1. Do you have feelings that you don't really care what goes on around you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very seldom or never Very often

M2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M3. Has it happened that people whom you counted on disappointed you? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never happened Always happened

M4. Until now, your life has had:

1-----2-----3-----4-----5-----6-----7
No clear goals or purpose at all Very clear goals and purpose

M5. Do you have the feeling that you're being treated unfairly? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M7. Doing the things you do every day is:

1-----2-----3-----4-----5-----6-----7
A source of deep A source of pain
pleasure and and boredom
satisfaction

M8. Do you have very mixed-up feelings and ideas? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M9. Does it happen that you have feelings inside that you would rather not feel? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom
or never

M10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Never Very often

M11. When something happened, have you generally found that:

1-----2-----3-----4-----5-----6-----7
You overestimated or underestimated its importance You saw things in the right proportion

M12. How often do you have the feeling that there's little meaning in the things you do in daily life? Please circle your response.

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

M13. How often do you have feelings that you're not sure you can keep under control?

1-----2-----3-----4-----5-----6-----7
Very often Very seldom or never

Q1. Did anyone assist you with the completion of this survey?

No _____

Yes _____ If yes, who? _____

Thank you for taking the time to fill out this questionnaire. Your answers are very important to us. They will help researchers learn more about the quality of life of prostate cancer patients and their families.

We appreciate the care you have shown in completing this survey! We will be mailing you the fourth questionnaire twelve months from your treatment and/or management initiation date